In re: National Football League Players' Concussion Injury Litigation, No. 2:12-md-02323

Good morning Judge Brody, members of the court. Thank you for this opportunity to submit my objections to the proposed settlement.

I am Dr. Mary Hawkins, (Ph.D., M.S., P.T.). I reside at 910 Prairie Ave., Cheyenne, WY. My date of birth is January 22, 1955.

I am the Representative Claimant and spouse of Mr. Ross C. Hawkins, also known as 'Rip,' who was the second round draft choice of the original Minnesota Vikings team. He served as co-captain and defensive captain and played for five seasons, from 1961-1965 until he chose to leave the team to complete law school at Emory University and to also direct his energy toward the care of his wife at the time who was ill and later died.

I come before you as wife and care partner for my husband, "Rip," as his representative. My husband can no longer consistently engage in this conversation with the same succinct robust quality that he may have as a player or co-captain, nor as he did in his subsequent career as an assistant district attorney. So I am here to offer a voice that shares his and my experiences, insights, and some unsettling concerns to the proposed agreement. I am attempting to articulate these objections in a manner that accurately reflects his perspective as I have known it over our 30 year relationship. In addition, I am here to present my concerns about a number of issues that have been overlooked as I understand the contents of the agreement. I am not a legal expert, but I have acquired a level of proficiency in my personal and professional experience that are relevant to the care of these former players and I believe my comments are worth consideration for not only for my husband but also for other former players who have or will be faced with similar circumstances. Your honor, and members of the court, I ask for your indulgence as I briefly share some of my personal and professional background that lends credence to my comments presented today. These comments also include data obtained from other resources.

I am a seasoned health care provider, who has for more than 40 years made advocacy my primary goal for those whom I have had the privilege to serve. My experience crosses several disciplines caring for clients and patients from newborn to geriatric; in all phases of health and fitness. As a health practitioner I hold certifications in respiratory therapy, massage therapy, and biofeedback therapy. I am also licensed in two states as a physical therapist. Across these care specialties I have served in acute and chronic care, including trauma units, rehabilitation of TBI (traumatic brain injury), neurologic diseases, and SCI (spinal cord injury), cardiac rehabilitation, pain management, and neonatal intensive care. I had the opportunity to work at the Denver Children's Hospital for 8 years; 4 years, as a coordinator of perinatal research in varied subjects, including a multi-center national collaborative study, as well as an NIH investigation.

I have also had the honor of accompanying patients and their families as a hospice volunteer, with an intentional focus on also serving the care partners and families of those in their end-of-life transition.

My career began as a health care provider when I was 18 years old. During my first semester at the University of Colorado in Boulder, majoring in physical therapy, my mother became seriously ill. I surrendered my full scholarship to care for her and my 4 younger siblings, ages 2-16. Four years later she sustained a massive stroke and was confined to a nursing home for 20 years until her death, while I continued to care for my siblings and raised my youngest sister, until she finished college. During the course of that time I completed my undergraduate and graduate studies. My educational experience recently culminated with the completion of my doctorate just as the most alarming neurocognitive symptoms were presenting in my husband. My dissertation research focused on the self-regulation and leadership practices for the management of cardiac care and stress-related dis-ease.

So in addition to my professional training I have more than 40 years of very personal experience in the care of neurodegenerative disease. But I will say, that my many years of experience, professionally and

personally, was not nearly enough preparation for my most challenging role, caring for my beloved husband as he progresses in his course of neurocognitive decline.

A neuropsychologist's "official" diagnosis of post-concussive dementia came for Rip only last year; 5 years after some of the most profound and alarming ongoing symptoms could no longer be ignored. (The symptoms of sleep disturbances were dismissed by physicians, including specialists, as "just dreams" rather than Rapid Eye Movement REM Sleep Disorder, a violent acting out of dreams and a cardinal sign of a major neurodegenerative disease).

With the onset of these atypical behavior changes, I began looking for answers and a possible intervention. In 2009, Rip was enrolled as a participant in the research conducted by the Center for the Study for Retired Athletes at the University of North Carolina, (his alma mater) under the supervision of principal investigator Dr. Kevin Guskiewicz. The study examined the effect of large doses of DHA (docosahexanoic acid, omega 3 oils) for Mild Cognitive Impairment (MCI) in former NFL players. During the nine-month period of his participation, Rip's testing score plummeted from the 76<sup>th</sup> percentile to the 6<sup>th</sup> percentile in one of the examined variables for vocabulary recall. Unfortunately, he was in the control group. The results of the study were inconclusive.

This was merely the beginning of our journey to acquire knowledge and a possible intervention.

Despite my medical acumen and relentless tenacity, this process was frustrating, slow, and arduous.

Valuable time was lost that could have been directed to more appropriate management of his progressing symptoms.

My initial contacts with the NFL Player Care Foundation, were among the stymied efforts. Primary care physicians were often dismissive and indifferent to my husband's symptoms and needs. After 4 years, rigorous neuropsychological testing was performed, and Rip was diagnosed with post-concussive

dementia. A year later a neurologist reassessed my husband's condition and offered a more specific diagnosis of Dementia with Lewy Bodies (DLB), with a very different pharmaceutical intervention. This new assessment was not based on the progression of symptoms in the intervening year, but rather, it included the same reported symptoms that spanned the previous decade. Our experience illustrates the difficulty of assessment and accurate diagnostics. And even before entry into the medical system, care partners are in dire need of education and support to recognize the signs and symptoms that warrant appropriate medical intervention.

This historical account of my husband and myself as care partner is both relevant and illuminating to the specific settlement objections that I submit today. I have not even detailed the devastating behavioral changes that are the current reality for my husband, but what I hope is clear in this narrative is the challenging task of arriving at a diagnosis so that appropriate care can be initiated. I cannot imagine the plight of those faced with this difficult task who do not have 40+ years of personal and professional medical experience or even know what questions to ask.

I am hopeful that the proposed Baseline Assessment Program will be a good beginning point for players and their partners to be directed to the appropriate health care. Perhaps it should be a *required* component of release from a player's NFL contract, not merely an incentive to avoid any discounting of future settlement awards. Requiring a standardized BAP with select measurement criteria would offer an invaluable data base that would be of great benefit.

While the Baseline Assessment Program (BAP) may provide exactly that, a baseline assessment, it is imperative that former players and their care partners have specific assistance to guide them through the care process. Early diagnosis and intervention has been demonstrated to improve patient outcomes. Nearly 80% of people with LBD for example, received a diagnosis for a different cognitive, movement or psychiatric disorder before ultimately learning they had Lewy body dementia (LBD),

according to the Lewy Body Dementia Association's new report, Caregiver Burden in Lewy Body

Dementias. This new report reveals people with LBD and their caregivers face barriers to obtaining
an early LBD diagnosis. Half of people seeking a diagnosis for LBD symptoms saw three or more
doctors for 10 visits over the course of a year before they were diagnosed with LBD, and diagnosis
required more than two years from the onset of symptoms for 31% of cases. Additionally, according
to this same article, caregivers experience moderate to severe emotional burden, and most
experience a sense of isolation because so few people know about LBD. The findings are based on
data collected by the Lewy Body Dementia Association (LBDA) in an online survey of 962 LBD
caregivers. Designed by Steven H. Zarit, PhD, an expert on caregiver burden in dementia and
Professor of Human Development at Penn State University, the survey was conducted over a 6month period. Dr. James E. Galvin, a member of LBDA's Scientific Advisory Council and Professor of
Neurology and Psychiatry at New York University, analyzed the survey data, which was published in
the July, 2010 issue of Parkinsonism & Related Disorders and the April-June, 2010 issue of
Alzheimer Disease & Associated Disorders. - See more at:

http://www.loda.org/node/417%sthash.4iLWEJCa.dpuf.

LBD, the second-most common form of degenerative dementia in the elderly affecting an estimated 1.3 million people in the United States, is most often misdiagnosed as Alzheimer's disease. (Despite its prevalence, there is no designated subcategory for a DLB diagnosis in the structured settlement.)

LBD is considered part of the Parkinson's spectrum, and it also as the name implies, has dementia as a core feature. Do players diagnosed with LBD fall in the category of Parkinson's or dementia in the settlement structure? It presents a puzzling conundrum. I do understand that there are as many as 50 different documented causes for dementia (WebMD) and that kind of specificity in the settlement structure is not a practical consideration. However, research conducted by Dr. Fredrik

Boström and colleagues in Sweden indicates that resource utilization in patients with DLB is significantly higher than those with AD. (December, 2006 issue of the International Journal of Geriatric Psychiatry).

DLB patients used more than double the amount of resources compared to AD patients. Specifically, DLB patients used greater resources in accommodations (long term residential care), and required more outpatient care, informal care (measured by caregivers' lost production and lost leisure time), community services and pharmaceutical therapy. AD patients utilized more inpatient care than DLB patients.

Apathy, along with other neuropsychiatric features was measured and found to be higher in DLB patients than AD patients. Cost of care for DLB patients with apathy was almost three times as high as in AD patients with apathy.

These findings were collected from the general population and do not even consider the psychosocial dynamics of former athletes, nor the typical large physical size that presents additional care management challenges.

See more at: http://www.lbda.org/aode/194 isthash.ivitxn3Knx.dpuf

While the BAP may offer an infrastructure to direct the assessment and intervention process; our personal experience and the data provided illustrate the manifold challenges in the assessment process.

I direct my attention to another feature of the proposed settlement that is directly relevant to the assessment challenges. The \$10 million dollars designated for education has been described in some reports as safety education particularly targeting youth football. For those who have been diagnosed

with a neurocognitive disease and those caring for them, it is little consolation that these education funds will allow the NFL to continue to market the game under the veil of enhanced safety. What would be more appropriate in terms of an informed choice, is education and public service announcements comparable to those mandated for the tobacco industry that graphically depicted the effects of smoking. Commercials showing these fallen heroes who no longer recognize their loved ones, who cannot walk, communicate, are incontinent, indigent, or confined to long-term care facilities would be a much more accurate and eye-opening depiction of the safety hazards and consequences of head injuries.

As a health professional who appeared before the Wyoming State Legislative Health and Human

Services subcommittee, lobbying for post-concussion return to play guidelines as early as 2010, I believe the prevention and safety education ship has already sailed. While I applaud these efforts, that must be continued, the need that has long been ignored is the education of players, alumni, families, and care partners to identify post-concussive symptoms and behaviors that warrant assessment, and the outcomes of these disorders. And when assessment or diagnosis is obtained, it is imperative that the care partners have on-going resources available to assist them in the strategies of safe and effective care. I have repeatedly made these suggestions to the NFL Player Care Foundation, I have offered my professional skills for support and training and have received a response to the effect of, "Great idea, we'll get back with you." (Personal correspondence, August 7, 2013, October 23, 2013, and December 5, 2013) Additional pleas were made almost 6 years ago to the PCF. I am proposing that the education and safety fund include education for the care partners. This is a direct benefit to the players. Educated and skilled care partners providing quality care results in lower health costs, improved quality of life, and delayed entry to long term care facilities. Carefully designed psychosocial and psycho educational interventions for caregivers may reduce stress and achieve a more positive outlook for themselves and

the dementia sufferer, allowing them to stay and be cared for in their own homes for longer (JBI, Assisting caregivers to support people with dementia, Best Practice, 14(9)2010).

The financial merits alone of caretaker education are obvious, not to mention the improvement to the collective quality of life and well-being for the care partner and recipient.

Also in a care-related area, there is another troublesome feature of the settlement. Currently the NFL 88Plan provides funding for in home care for those approved by the plan, but such services cannot be reimbursed for care provided by a family member. Many families are making tremendous sacrifices to provide family care to keep their loved ones at home for as long as possible. The care is provided at tremendous risk to not only the health of those caregivers, (BTW caregivers die at a rate 64% higher than people the same age who are not caring for someone with dementia (Schulz,R. and Beach, S..., "Caregiving as a Risk Factor for Mortality: The Caregiver Health Effects Study," *American Journal of Geriatric Psychiatry 12*, no. 3 (May-June 2004): 240-248). In fact 30% of the care partners die before, the care recipient according to Sharmone La Rose who teaches Caregiver Training at Torrance Adult School, held in collaboration with Torrance Memorial Medical Center.

(http://www.torrancenamorial.org/News\_Capter/Pulce/2012/The\_Cacegivers\_Challenge.aspx).

In addition to the physical toll on these care partners, the demands of caregiving represent a significant financial burden to the collective assets of the families affected by these illnesses. This is a direct loss to the former player. Turge a change in the current 88Plan guidelines to allow for the reimbursement of care services provided by loved ones related to the former player.

My next concern is related to the distribution of the settlement funds. On page 12 of the 2011 Special Edition of the NFL Alumni, *Legends* publication, it was reported that "50% of retired NFL players divorce within one year of retirement, and 78% have gone bankrupt or are under financial stress within two years." Certainly, there are myriad causes for this data that are not the subject of this dialogue.

Nonetheless, I am confused and dismayed that given these alarming data for players at 2 years post-retirement or less, there has been no mention of a custodial methodology for distribution of settlement funds in this case, given the cognitive status of settlement recipients. The NFL has sent a clear precedent in its practices for assisting other alumni, (who are presumably without cognitive impairment) with active programs for re-entry into careers upon retirement with funds that are available for post graduate training. They have also implemented a program to assist alumni with financial investment strategies, business development and other benefits. It is disappointing and even shocking that there is no mention in the settlement agreement for any form of support services for this population with obvious cognitive impairment or other limitations that would make their management of financial assets tenuous at best. As a representative claimant, I would welcome the availability of resources to determine the most judicious stewardship of any settlement assets for my husband.

My final objection that I present today relates to what I believe is the prejudicial nature of the settlement distribution based on player age. While age is certainly recognized as a factor in the development of neurocognitive disease, these older alumni are being penalized for the fact that the medical discoveries and the awareness of neurodegenerative diseases related to head trauma did not exist decades ago, even though for many players, their unrecognized and untreated symptoms were prevalent. What did exist was a culture of bravado that fostered the denial of pain and symptoms, and rewarded these men for their stoicism, often with the administration of pharmaceutical agents that contributed to their long-term sequellae. I maintain that the cultural mindset of stoicism has persisted, particularly among the older alumni, and that despite the physical and neurocognitive consequences of their years in football, their pride and honor; (what this football league was built on) has overshadowed their willingness to admit their past and current needs or their vulnerability. Many are reticent in expressing their limitations, believing that any admission of their current hardships is a source of weakness and shame. What is a shame is the fact that knowingly or unbeknownst to them, many have

suffered diminished capacities for decades; personally, professionally, psycho-emotionally, behaviorally, financially, and interpersonally. There was no metric for understanding these dynamics, or the consequences of repeated closed head trauma. But with the progression of neurocognitive deficits, in conjunction with age, the insidious precursors have zero compensatory value for their subtle to ravenous effects, and the current neurologic condition of these geriatric players is being compensated as a function or consequence of age, not for its often unrecognized or protracted development that for many came a great cost to them and their families.

Judge Brody, members of the court, I thank you for the opportunity to share my concerns.

Respectfully,

Mary Hawkins

October 14, 2014

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